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The caregiver adaptation research evaluation scale (CARES) a pilot study

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THE CAREGIVER ADAPTATION RESEARCH EVALUATION SCALE (CARES)

A PILOT STUDY

A Thesis

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By

Maureen Vaughan Ruscher

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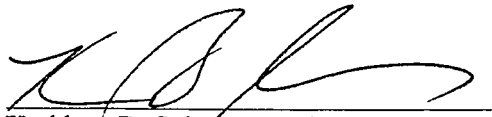

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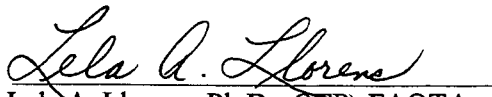

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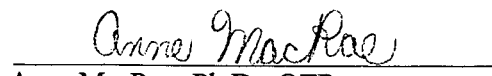

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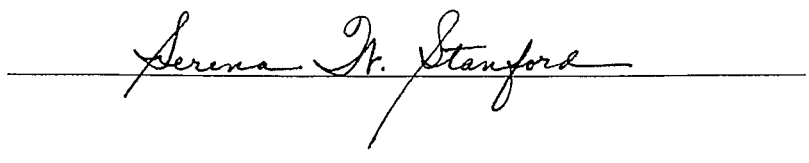

ABSTRACT

THE CAREGIVER ADAPTATION RESEARCH EVALUATION SCALE (CARES)
A PILOT STUDY

by Maureen Vaughan Ruscher

This study portrays the development of the Caregiver Adaptation Research Evaluation Scale (CARES), using the Model of Human Occupation as its foundation, to assess areas of occupational function and dysfunction among individuals assuming the role of non-professional caregiver. A pilot study on caregivers to individuals with the Human Immuno-deficiency Virus (HIV) illness was implemented to determine the usefulness of CARES.

Research findings indicate that the CARES is a viable instrument to determine occupational function, dysfunction and areas at risk of dysfunction among non-professional caregivers. Occupational dysfunction was apparent in all of the sub-components of the Model of Human Occupation. Topics for intervention are included.

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TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES

Chapter 1

INTRODUCTION

Purpose

The purpose of this study was to develop a research instrument using the Model of Human Occupation which would enable therapists to assess areas of occupational function and/or dysfunction among non-professional caregivers. The research was also intended to determine the usefulness of the Caregiver Adaptation Research Evaluation Scale (CARES) by testing it in a pilot study.

Statement of Problem

According to Woods (1991), it has become evident that there is an increasing number of individuals and family members assuming the role of caregiver. This occurrence is changing the traditional meaning of caregiver to go beyond trained health care providers. In 1989, 2.2 million Americans were serving as informal caregivers (Scharlach, 1989). Most of these caregivers received no professional training. As the number of caregivers continues to grow so does the demand for services for these individuals. Adequate resources must be made available to evaluate and support this population.

Much research has been conducted to study the needs caregivers to individuals with many different diagnoses. The diversity of research instruments is nearly as great as the diversity of the diagnoses. Most measures have been used to calculate the strains and burdens that caregivers experience. Indications are that care giving is a stressful endeavor. What is less clear is whether these caregivers are being assessed adequately to

enable proper interventions to be effective. Current assessments and literature indicate that all areas of the individuals' lives are not being examined.

Before professionals can provide intervention to caregivers, they must be able to assess all of the caregiver's needs. Needs assessments have been conducted by nurses, social workers, and doctors covering the needs of caregivers to individuals with Alzheimer's Disease, chronically ill children, people with dementia, brain impaired adults and Hospice members. They have explored such areas as: subjective feelings regarding caregiver burdens (Novak & Guest, 1989); primary health care needs such as health promotion, illness management, and developmental tasks (Dragone, 1990); characteristics of caregivers (Friss, 1990); and relationships between caregivers and the recipients of care (Etten & Kosberg, 1989). The difficulty with these assessments is that they do not permit the distinction between the dimensions of burden. No assessment tool has been located and/or developed which looks at the caregivers from a holistic point of view, assessing the individuals' unique needs and abilities as well as the environmental and social factors affecting the caregiver's performance and satisfaction.

Occupational therapists are in a unique position to assess these components in their entirety as functional performance is a key element to occupational therapy. In occupational therapy, the focus of function extends to an individual's ability to perform occupational roles, tasks, and activities in the context of their social and environmental milieu. While occupational therapy has a battery of assessments that look at such areas as activities of daily living, adaptive skills, cognitive skills, developmental skills, interests and leisure activities, motor skills, oral function, person-environment interaction, play skills, psycho-social needs, roles and habits, sensory integration, visual-perceptual skills and vocational skills (Asher, 1989), the profession is lacking a holistic assessment that looks at all the areas, especially as they relate to a viable frame of reference. Without

proper assessment tools health care professionals will be unable to efficiently and adequately provide services to the growing population of non-professional caregivers.

Objectives

The objectives of this study were:

1. To develop a research instrument, based on the Model of Human Occupation, which could be used to determine occupational function and or dysfunction among non-professional caregivers
2. To subject the Caregiver Adaptation Research Evaluation Scale to a pilot study.

Research Question

The question to be answered by the research was:

Is the Caregiver Adaptation Research Evaluation Scale effective in determining occupational function and occupational dysfunction?

Definitions

The following definitions have been generated for terms used in this study that may be unfamiliar or open to interpretation.

Adaptation: "any adjustment or change of behavior in response to the challenges or demands of living" (Christiansen, & Baum, 1991, p. 32).

Caregiver: The person primarily responsible for providing regular assistance and attendant care including such tasks as physical labor, and responsibilities of companion, case manager, and solicitor of outside additional care.

Caregiver Adaptation Research Evaluation Scale: Instrument designed by author to determine occupational function and/or dysfunction among non-professional caregivers.

Dysfunctional adaptation: The progressive reduction or disruption of the system components which preclude satisfactory role performance as indicated by experiences of disorganization, poor performance and the anticipation of future failure (Christiansen & Baum, 1991; Cubie & Kaplan, 1982).

Environment: The external social and physical conditions or factors which have the potential to influence an individual (Christiansen & Baum, 1991).

Functional adaptation: The progressive development of the system components which enhances satisfactory role performance and the desire to explore, to master, and to fulfill the environmental demands (Christiansen & Baum, 1991; Cubie & Kaplan, 1982).

Habits: Images guiding routine and typical ways in which a person performs; behaviors within a role but not specifically required by the role (Kielhofner, 1985).

Interests: Dispositions to find occupations pleasurable (Kielhofner, 1985).

Occupational dysfunction: When an individual's "a) societal demands and expectations for productive and playful participation are not met and/or b) behavior does not fulfill the urge to explore and master or threatens the disruption of the systems' components"(Kielhofner, 1985, p. 64).

Occupational function: When an individual is able to "(a) act so as to satisfy society's expectations and need for productive and playful participation, and b) act so as to allow expression of exploration and mastery, and maintenance and enhancement of personal causation, values, interests, roles, habits, and skills and their constituents (Kielhofner, 1985, p. 63).

Personal causation: Beliefs/expectations which a person holds about one's effectiveness in the environment (Kielhofner, 1985).

Roles: "Images that persons hold of themselves as occupying certain statuses or positions in social groups and the obligations or expectations that accompany being in these role" (Kielhofner, 1985, p. 24).

Skills: Collection of abilities (1) to interpret sensory information and manipulating self and objects, (2) directed at managing events or processes in the environment, and (3) for sharing and receiving information and for accomplishing mutual activities and goal (Kielhofner, 1985).

System components: Subsystems which make-up a human being including personal causation, values, interests, roles, habits, skills and environment.

Values: Images of what is good, right and/or important (Kielhofner, 1985).

Assumptions

In undertaking this research, the following assumptions have been made:

1. The Model of Human Occupation is a reliable frame of reference which allows the description of both organized and disorganized behavior and the examination of a continuing process of change (Cubie & Kaplan, 1982).

2. The collection of data pertaining to the way that non-professional caregivers are adapting in their roles is important to health care professionals.

3. The role of caregiver represents a stressful event that requires adaptive responses.

4. Dysfunctional adaptation can be remediated.

5. There is an opportunity for occupational therapists to facilitate functional adaptation.

6. The client is a fundamental part of the therapeutic process.

7. The subjects involved in the pilot study will be able to understand the questions asked of them and respond honestly and to the best of their ability.

Limitations

The following limitations must be considered when reviewing the data and conclusions drawn from this study:

The small sample size is a limitation to the study. The method of selecting the subjects for the sample is another limitation. A convenience sample is a non- probability sample which does not eliminate the possibility of bias. All subjects were participants in either a caregiver support group or a training seminar for caregivers. An additional limitation is that the survey relied on a self-report. Self-reports may be influenced by current psychological feelings and perceptions of stress at a particular point in time.

Significance of the Study

The rising incidence of family members and friends assuming the role of non-professional caregiver has fostered the need to explore how these individuals are adapting to ensure that optimal independence in life tasks are occurring. The importance of effective adaptation cannot be overemphasized since successful adaptation equates to quality of life. This concept is basic to most occupational therapy theories (Reed, 1984). Furthermore, for effective adaptation to occur, there must exist a medium which explores the components that facilitate satisfaction with one's occupational roles, tasks, and activities in the context of their environment.

The 1980's and 1990's have created an increasing demand for occupational therapy (OT) services. While the population of non-professional caregivers is but one group in need of OT services, it is a population where there exists a dearth of information about the caregivers' needs from a holistic point of view. Key to the lack of information is the existence of a reliable encompassing assessment tool. In 1968, West stated that "it matters most of all that we (OT) recognize the responsibility of the profession to change with changing demands for its services, to adapt via new approaches, and to assume different roles" (p. 14).

This study has presented the profession of occupational therapy with an arena to assume new roles. Occupational therapists are being encouraged more and more to further validate the profession through research efforts. The role of researcher is being utilized to demonstrate the value of effective assessment tools, the review of the findings , the implications for interventions, and finally the therapeutic effectiveness of the practice.

New services and treatment approaches are also being presented in this arena. The development of an effective tool based on an occupational therapy frame of reference provides a service not just to the profession of OT, but potentially more globally to other

healthcare professions involved with caregivers as well. An established tool would further enable new approaches to be made to assist in remediating dysfunctional adaptation as uncovered through evaluation of the client from an unique Occupational Therapy frame of reference. With new services and treatment approaches, the role of occupational therapists continues to grow.

Finally, it is through the administration of assessment, the application of treatment and reassessment that practices can be validated. The development of the Caregiver Adaptation Research Evaluation Scale (CARES) and the pilot study of its efficacy can contribute to the research needed in this area.

Chapter 2

LITERATURE REVIEW

Introduction

Information generated from the literature search was divided among 5 areas: (1) caregiver research, (2) assessments of non-professional caregivers, (3) Occupational Therapy research on caregivers, (4) Occupational Therapy assessment tools, and (5) the Model of Human Occupation.

The Status of Non-Professional Caregivers

Caregiver Research

In 1981, researchers were beginning to become aware of a major national problem. That problem was the long-term care of chronically impaired persons (Goldstein, Regnery, & Wellin, 1981). At that time David Mechanic predicted that the care of chronically ill and disabled individuals loomed as " the most significant future problem in health services" (as cited in Goldstein et al., p. 24). The majority of these individuals are living in communities as opposed to institutions. Goldstein et al. (1981) reports that " of the entire elderly population, only about five percent live in institutions... Even among the bedfast and homebound elderly, between two and three times as many are at home as are in institutions" (p. 25). The individuals who are caring for these physically challenged persons are not trained health care professionals, but rather family and friends. The term caregiver has had to be extended to cover the professionally trained healthcare providers as well as the non-professionally trained healthcare

providers. The early 1980's were unable to provide much information on the growing number of non-professional caregivers and the problems they encountered.

The early 1990's provided little more research on caregivers, except that their numbers were continuing to grow. Musolf (1991) states that "the number of people placed in care giving roles has been increasing steadily since the early 1980s" (p. 82). Scharlach (1989) cites that in the United States alone, 2.2 million Americans are serving as non-professional caregivers for elderly, ill or disabled persons. Reasons given for the increase include, but are not limited to the implementation of diagnosis-related groups (DRGs) which limit the number of days a patient can stay in the hospital, which results in patients being discharged to the care of family members for continued care at home and nursing homes who as well have made their stay requirements more stringent and more costly, turning away populations previously accepted in the past (Musolf, 1991; Wood, 1991).

Turner and Pearlin (1989) acknowledge "that while informal care probably lowers financial costs at the community level, it is not without personal costs to those who take on the caregiver role" (p. 58). In becoming a caregiver virtually all aspects of ones life are affected. Turner and Pearlin (1989) identified three areas of stressors. The first they termed primary caregiver strains which included the issues that arise directly from the caregiver role itself. The multiple household and managerial tasks associated with the personal care of the patient were related to the time pressures, periods of exhaustion, and concerns regarding ones ability as a caregiver that an individual experienced. The secondary strains consisted of circumstances such as financial strains, work issues, and decreased involvement in valued social and leisure activities as a result of providing care. Intrapsychic strains was the third area identified. These strains were seen within the

individual and included personal feelings and beliefs about ones self worth and concerns about the anticipation of the loss of a loved one.

Some of the roles assumed by caregivers include, but are not limited to providing financial management, meal preparation, grocery shopping, transportation, medication , wound care and assistance with personal care, skin care, physical management, and psychological support (Hinds, 1985; Musolf, 1991; Rose & Catanzaro, 1989; Wood, 1991). These new roles have an impact on an individuals prior level of functioning from a personal level through their dynamic interaction with others..

One of the most critical issues for caregivers is burnout. Particularly for individuals who ignore their own experiences as they deal with increasingly complex problems (Cline, 1990; Jimenez & Jimenez, 1990).

Scherlach (1989) studied the impact that caregiving had on an individual from private life to work life. The research indicates that on a personal level the biggest effects are those regarding one's privacy, time for self, and time for social activities including time with family and friends, volunteer work , and religious activities. On the work front time is taken up with paid and unpaid days off, phone calls made during work, and time missed for transporting individuals to medical appointments. General fatigue is also mentioned as affecting work performance. In some cases full-time work has to be cut back to part-time work in order to fulfill the caregiver role . Cutting back hours affects individuals both emotionally and financially (Musolf, 1991).

According to Hinds (1985) it has been acknowledged in the literature that families providing care to ill or disabled loved ones places caregivers in a vulnerable and stressful environment, and yet little attention or effort has been spent of examining the needs and responses to the caregiver role. In her study on the needs of families who care for patients with cancer at home, Hinds attempts to address such issues as they relate to

the needs of the family as they provided physical care. Several areas of need were discovered to be unmet.

In the areas of activities of daily living, 31% were found to be coping poorly; 27% needed guided assistance; of that 27%, 12% felt they had received the necessary guidance while 15% felt their needs were unmet (Hinds, 1985). Hinds surmised that many of "the families felt inadequately prepared to cope and that they had informational and skill needs" (1985, p. 578).

Regarding family members' psychosocial needs finances, affect, psychological and respite needs were identified. Sixteen percent of Hinds' population reports needing financial assistance. Affective needs break down into a lack of closeness to the patient, decreased communication, and problems with sexual relationships. Fifty-three percent who were polled identified multiple psychological stresses which were often not resolved. These stresses included feelings of insecurity about one's ability to provide basic patient care, uncertainty about the disease course, how to handle the patient's depression, impatience and anger, making adjustments to the new role, lack of time, and dealing with the possibility of the patient's death (Hinds, 1985).

Hinds (1985) also provided her population with the opportunity to openly express any other concerns not addressed in her survey, 72% responded with additional comments and concerns. Despite a lengthy interview, a full and comprehensive examination of the families needs was not achieved. Hinds concluded that the need for a mechanism that would reveal areas of need and allow for intervention which could be used periodically as an initial and up-dateable assessment was necessary to provide assistance to family caregivers.

Assessment of Non-Professional Caregivers

The earliest assessment instrument for use with caregivers was found in a study conducted by Kasper and Nyamathi in 1988 that studied parents of children in the pediatric intensive care unit. The study used a semistructured interview based on parental role theory and crisis theory and explored parents' perception of their needs. Two hundred and eighty needs were expressed and broken down into three categories. Fifty-eight percent were psychological needs, 27% were physical needs and 15% were sociological needs (Kasper & Nyamathi, 1988). The authors concluded that the needs of these parents must be further investigated through the development of a more refined interview guide.

Etten and Kosberg (1989) utilized two assessment tools to conduct their research on the hospice caregiver. The Hospice Caregiver Assessment Inventory (HCAI) and the Caregiver Intervention Plan (CIP) were implemented to evaluate role and interrelational problems identified for these caregivers. The use of these tools identified nine major domains: (1) personal information disclosed demographic data; (2) caregiver support system looked at the presence of informal supports; (3) relationship between caregiver and client assessed the quality of the relationship in terms of positiveness, happiness, and dependency; (4) importance of the dying person relative to the caregiver's ability to maintain the activities of daily living for each other and the household; (5) communication explored the nature and quality of communication between the caregiver and the client; (6) impact of terminal condition - caregiver's perceptions about the patient's condition are assessed; (7) the role of caregiver was analyzed and included such areas as technical knowledge, emotional capability, and physical strength; (8) caregiver's perception of death as it impacts the caregiver's ability to personally face the prospect of their own mortality; and (9) experience with loss through death or other events explored

how individuals cope with loss and who, if anyone, assists them. The combined implementation of these two assessments resulted in increased attention directed at the psychosocial needs of caregivers (Etten & Kosberg, 1989).

The Norbeck Social Support Questionnaire (NSSQ) was utilized by McGough (1990) as a tool to diagnose, set goals and interventions and to evaluate one's social support needs. Through her research McGough reaffirmed the importance of social support systems and its relationship to health, physically and emotionally. Such an assessment is believed to be useful in health promotion and prevention (McGough, 1990).

Rawlins, Rawlins, and Horner (1990) acknowledged that numerous assessment tools exist that look at family coping and functioning, but reported that certain areas were missing from the assessment of caregivers, hence the development of the Family Needs Assessment Tool (FNAT). The authors identified a dearth of information regarding special information and service needs. In assessing the needs of parents of chronically ill children they stressed that needs will vary with each individual and therefore they emphasized the importance of obtaining information from the caregiver instead of the perceptions of others. Their research indicates, that accurate information is of primary importance, seconded by the need for easier access to medical care, and the identification of available special services.

In response to the numerous unidimensional caregiver burden scales which explore caregiver's feelings and experiences, health status, financial strain, social activity, and changing feelings, Novak and Guest (1989) developed and implemented the Caregiver Burden Inventory (CBI) in an attempt to create a diverse and multidimensional instrument. The purpose of the CBI was to permit distinction between the "dimensions of burden." Five factors with a total of 24 questions make up the CBI. The first factor, Time-Dependence Burden, describes the burden as a result of restrictions on the

caregiver's time. Developmental Burden is the second factor and explores the feelings of caregivers in terms of their being off in their development in respect to their peers. Factor three, Physical Burden recounts the caregivers' feelings of chronic fatigue and damage to physical health. Factor four, Social Burden explores the caregivers' feelings of role conflict. The final factor is Emotional Burden, which describes the caregivers' negative feelings toward their patients including guilt and resentment.

Care is being provided to a wide variety of patients/clients, and while symptoms may vary, the impact on the caregivers is monumental regardless. Screening tools cannot be used to make diagnoses, but they can be used to identify those at risk and thus in need of more in-depth assessment and appropriate intervention.

Occupational Therapy Research on Caregivers

The early twentieth century saw the genesis of occupational therapy. A distinguishing characteristic of occupational therapy then and now is that health is viewed in the context of life performance. Christiansen (1991) notes that "life satisfaction is not determined by the momentous events that make significant marks in our memory (weddings, graduations, promotions, etc.), but rather from our everyday tasks of living or occupations, which we take for granted until their accomplishments become difficult or improbable" (p. 4). Caregivers, as acknowledged and supported in the literature from other health professions, are individuals at risk for poor life satisfaction in context of their life performance based on the many strains, burdens and hardships they have reported.

A review of occupational therapy literature revealed that apparently there has been very little research done by the profession which looks at caregivers or assessments which could be utilized to explore caregivers' needs.

Hasselkus (1988, 1989, 1991), a registered occupational therapist, has explored such areas as the meaning in family caregiving, the meaning of daily activities, and ethical dilemmas from an OT perspective. Research on the meaning in family caregiving categorized several problem situations. The two major headings were themes of meaning and tensions. The first theme of meaning was the issue of a sense of self. Caregivers expressed concern about their ability to care for themselves, questioned their capabilities, and showed an increased sense of personal causation. The second theme was one's sense of managing. Managing was measured in orderliness and cleanliness, ability to get enough activity, ability to get things done, and a concern about finances. Sense of future, another theme, explored the sense of doom for both the care receiver as well as the caregiver. Sense of fear and risk were also identified, associated primarily with the fear of change and the attempts made by the caregiver to maintain a status quo environment. The theme regarding sense of change in role and responsibility was tied to the personal relationships the caregiver had with the care receiver. Most commonly identified was the loss of role from the previous relationship (e.g., wife, daughter, etc.). Tensions were identified between caregivers and care receivers, caregivers and other family members, and caregivers and health professional (doctors, nurses, therapists) (Hasselkus, 1988). Hasselkus (1988) concluded that further research was necessary to investigate the experiential aspects of caregiving to further enhance the abilities of both the formal and informal caregiver.

Hasselkus' 1989 research attempts to increase the knowledge about the meaning of daily activity to family caregivers to the elderly and derived three primary goals. The first goal is to get things done. Regarding getting things done caregivers expressed a lack of time and energy, some had to quit jobs, while others had to give up enjoyable social and leisure activities. Health and well being for the care receiver was the second

goal identified. Of first and primary concern was one's physical health followed by the responsibility to provide a variety and balance of activities in the care receiver's everyday lives for their psychological health. Health and well-being for the caregiver was the final goal. Caregivers expressed concern regarding their physical abilities and limitations as well as their emotional well-being.

A further attempt was made by Hasselkus (1991) to attempt to increase the understanding of the meaning of a caregiving experience in the hope that, with increased understanding, health professionals could better work with caregivers. An exploration of ethical dilemmas revealed five themes: (1) fear of violating an ethical principle; (2) a sense of current violation of an ethical principle; (3) negotiation within a principle; (4) negotiation between principles; and (5) one principle overruling another.

The involvement of occupational therapy with caregivers has been acknowledged by the nursing profession by the inclusion of their research in physical and occupational therapy journals. Williams-Schroeder (1985) explored meeting the needs of the Alzheimer's caregiver and identified five areas of need. Educational needs were identified first, highlighting the need for acquisition of information regarding activities of daily living (ADL). ADL should include communication, feeding, bathing, toileting and exercise. Physical needs for the caregiver included getting enough rest, learning to set limits, and exploration of issues arising over sexuality were identified as factors in the second area of need. The third and fourth areas of need were identified as emotional and social. Emotions must be acknowledged and expressed in a safe environment with a supportive person. As had been shown in the literature, social contacts are frequently curtailed by the caregiver in order to meet the needs of the care receiver resulting in social isolation. Leisure activities and socialization generally leave the caregiver with a

better sense of self-fulfillment. The fifth area of need identified was the need for professional services.

Occupational therapy is a profession which addresses all of these issues from a holistic point of view. Occupational therapy has maintained its commitment to helping people cope with the challenges of everyday living with a focus on health and well-being. While many identify occupational therapists who work with those limited by physical and emotional illnesses, congenital defects, accidents, and the aging process, few may recognize their current involvement dealing with environmental restrictions. Caregivers are a population which involve most of these areas and yet have been under represented in research and treatment. Research indicates that it is time for a full assessment of caregivers needs to be developed.

Occupational Therapy Assessment Tools

Occupational therapists currently have a battery of assessment instruments which could be used to begin an assessment of caregivers needs to determine how well they are adapting to their new role, but to date there is no comprehensive tool which combines the usefulness of current assessments with an established frame of reference.

Current instruments can be divided into areas of assessment which include, but are not limited to, interests, roles, interaction with the environment, management of daily activities, sense of self-esteem, hopelessness, and feelings of control. Interest check lists explore one's interests, values, and involvement in leisure/social activities. Role check lists explore the variety of roles past, present, and for future consideration, and the value one places in these roles. Environmental questionnaires focus on characteristics in one's living environment and the individual's perception of constraints and positive qualities in the setting. An activity configuration can demonstrate how individuals spend their time

throughout the day and on what activities. The Hopelessness scale assesses three factors: (1) affect or feelings about the future; (2) lack of motivation; and (3) future expectations. Self-Esteem scales describe positive and negative feelings about oneself including feelings of competence and efficacy. An internal-external scale measures belief in internal or external control over events (Kielhofner, 1985).

Model of Human Occupation

The Model of Human Occupation has been set forth as a viable theory which presents the unique orientation and expertise of occupational therapists while also drawing on models from other disciplines. This theoretical model provides a representation of various components and processes that underlie occupational behavior (Kielhofner, 1985). As a model its purpose is to provide a concise and coherent way to view the functioning and occupational behaviors of human beings (Pizzi, 1990).

Kielhofner (1985) expanded the concepts of the occupational behavior frame of reference into a model of the occupational nature of human beings. The model is intended to organize and represent the processes which comprise occupational function. Kielhofner states that occupational therapy "is concerned with the adaptation of persons in terms of their occupational function and dysfunction" (p. 63). When applied to caregivers, this model can be used to develop a comprehensive instrument to determine how individuals are adapting by examining a variety of human components identified and categorized in an established frame of reference.

Human occupation, developed by Kielhofner and Burke (1980), draws upon the theory of open systems and the developmental model. The model identifies humans as open systems who interact with the environment through a process of input, throughput, output, and feedback. Occupation is said to be the output of the system which consists of

work and play, and is motivated by humans urge to explore and master the environment (Kielhofner & Burke, 1980; Pizzi, 1990; Reed, 1984).

The Model of Human Occupation describes the human being composed of the interaction of three hierarchically arranged subsystems -- volition, habituation, and performance -- which interact with the environment (Kielhofner, 1985). The model is intended to encourage a holistic rather than reductionistic approach to analysis of occupational function.

The volitional subsystem is defined as "an interrelated set of energizing and symbolic components which together determine conscious choices for occupational behavior" (Kielhofner, 1985, p. 14). Personal causation, a subcomponent of the volitional subsystem, identifies the beliefs and expectations that a person holds regarding their effectiveness in the environment. This, in turn, is comprised of one's personal belief in their skills and the efficacy of those skills in meeting the challenges of the environment, including expectancy for future success or failure (Kielhofner, 1985).

Role functioning, a subcomponent of the habituation subsystem, has been described as the source of output in the system. While role performance is dependent upon adequate support of performance skills, the third subsystem, role functioning, is also controlled and directed by the higher level functions of the volitional subsystem: personal causation, values, and interests. Roles are defined as the "images one holds about oneself as occupying certain status's or positions in social groups and the obligations and expectations that accompany being in those roles" (Kielhofner, 1985, p. 24). Roles are based on perceived incumbency, internalized expectancy and role balance. The second subcomponent of the habituation system is habits. Habits are images guiding the routing ways in which a person performs. Habits organize skills into larger purposeful routines that create an automatic response (Kielhofner, 1985).

At the lowest level of the hierarchy skill is connected to performance. Skill provides the basic capabilities that cause action. Caregivers are called upon to provide many skills. Some of the skill components that caregivers require include process skills and communication/interaction skills. Caregivers demonstrate process skills in their ability to direct and manage events demonstrating problem solving and problem planning. Caregivers must also demonstrate ability to communicate with other people and the ability to coordinate one's behavior with others in order to accomplish mutual goals for the care recipient (Kielhofner, 1985). These skills are essential to the interaction of all subsystems that produce occupational function.

Environment is also highlighted by Kielhofner as a major contributing factor which effects occupational performance. The physical environment as well as the social environment of the caregiver must be considered. It is important to determine if there is too little or too much challenge and whether the environment fosters internal control. Individuals must be challenged enough to practice new roles, but if they are too demanding, occupational dysfunction is possible (Kielhofner, 1985).

Any change in a system is a result of the interaction of these subsystems. Change will require adaptation in order to fulfill the environmental demand (Kielhofner & Burke, 1980; Pizzi, 1990). A change in an individuals' role is occurring as people become caregivers. This disturbs the balance of each person's occupational function in at least one, if not more, of the subsystems. The Model of Human Occupation is an appropriate method to determine whether individuals are adapting functionally or dysfunctionally to the added role of being a non-professional caregiver. This model, with its comprehensive view is a viable stepping stone for creating an instrument which will assist in this endeavor while at the same time providing a frame of reference for treatment implications.

Summary

Research has indicated that indeed the number of non-professional caregivers is increasing and that the demands placed upon these individuals affects their lives and their ability to function in numerous arenas and capacities. Less clear are the criteria used to identify the degree of functional adaptation. Health professionals have attempted to address selected issues through assorted assessments. Open-ended questions have been used to ascertain areas of psychological needs, physical needs and sociological needs in a general manner (Kasper & Nyamathi, 1988). Others have developed instruments looking at specific components such as roles and interrelational problems or social support systems (Etten & Kosberg, 1989; McGough, 1990). Others have acknowledged the numerous variety of assessments available, but felt them insufficient, hence added more assessments to cover multi-dimensional aspects as well as focusing on individuals reported needs versus others perceptions (Novak & Guest, 1989; Rawlins, Rawlins, & Horner, 1990). Even with all of these assessments, one has yet to be produced that combines a comprehensive, holistic view of the caregiver which adheres to an established model. Occupational therapy has developed assessments, some based on theory, which begin to address assessing the caregivers occupational function, but one comprehensive and concise instrument is still missing. Using the Model of Human Occupation as a frame of reference and theory which looks at an individual holistically is the next necessary step towards developing an instrument to assess caregivers in order to determine possible therapeutic interventions.

Chapter 3

Design and Methodology

The primary goal of this project was to develop a research instrument using the Model of Human Occupation to facilitate determining occupational function and/or dysfunction among non-professional caregivers . The second goal was to conduct a pilot study to test the usefulness of the instrument.

Research Question

The question to be answered by the research was:

Is the Caregiver Adaptation Research Evaluation Scale effective in determining occupational function and occupational dysfunction?

Instrument Design

A review of the literature on caregiver assessment instruments was conducted. No valid instrument was found that provided a comprehensive and concise evaluation of a caregiver's degree of occupational function. In attempt to capitalize on the efforts of a variety of health professionals' assessments, it is assumed that the areas identified in these assessment tools are captured in the content areas as represented in the components utilized in the Model of Human Occupation.

Rating System

The Likert format is the most commonly used in the development of attitude scales in social sciences, hence was selected for application in this research instrument

(Benson & Clark, 1982). Similar to the Likert scale, five options for responses ranging from excellent to very poor and very valuable to no value were utilized with the value of five assigned to excellent/very valuable and one assigned to very poor/no value. A higher score was therefore indicative of caregivers' more positive perception of their attitudes and beliefs and hence functional adaptation. Not all questions involved a rating scale. Check lists were utilized to minimize open-ended questions in attempt to create uniformity. Caregivers were asked a few open-ended questions at the end of the survey to provide them with the opportunity to express their thoughts and feelings regarding factors they felt have either facilitated or inhibited their adaptation process, with the option to provide suggestions on what could further facilitate functional adaptation in one's occupational performance.

Instrument Testing Methodology

To establish content validity and comprehensiveness, experts from the field of occupational therapy were contacted to critique the Caregiver Adaptation Research Evaluation Scale. Practicing registered occupational therapists (OTRs) with backgrounds in research and specializing in the Model of Human Occupation were asked to determine to the best of their ability whether: (1) the items were clearly written, (2) the items held relevance to the study objectives, (3) the items conformed to a selected format, (4) the response options for each item were plausible, and (5) the wording would be familiar to the target group. A marketing researcher, familiar with questionnaire design was asked to provide the same service as the OTRs. The instrument was revised on the basis of feedback provided by said professionals. Once content was clarified, a qualitative examination was conducted using subjects considered to be representative of the target group. Two non-trained, paid professional caregivers agreed to critique the instrument.

These caregivers' participation in the test of the assessment provided information regarding actual time for administration and clarity of directions and questions. Additional revisions were made on the basis of their feedback before initiation of a pilot study. Approval to involve human subjects was granted by the San Jose State University Human Subjects Review Intitutional Board.

Pilot Study

The population selected to test the instrument through participation in a pilot study comprised caregivers for individuals with the HIV illness. The term AIDS became popular in 1982. Since then the number of people with the HIV illness has grown and grown as have the number of individuals needed to provide care for these newly diagnosed individuals. The U.S. Public Health Service estimates that between 1 million and 1.5 million people in the United States are infected with the HIV illness, and the Center for Disease Control (CDC) has projected that the annual incidence of AIDS will increase to 365,000 by 1992 (Heyward and Curran, 1988). The literature has shown that researchers have begun to address caregivers' needs to many individuals with assorted diagnoses since 1982; but, the diagnosis of HIV illness has not appeared in any of this literature. This researcher believed that due to the research location of the San Francisco Bay Area and the as-yet undocumented inclusion of research regarding the caregivers to individuals with the HIV illness, there would be an ample number of participants available for the study.

Description of the Sample

The subjects for this study consisted of adults who have had or continue to have contact with a local Bay Area AIDS support group or agency. Caregiver participation was requested in newsletters published by such agents (see Appendix A) and by personal request of the researcher at support group functions. Each person who volunteered to

answer the questionnaire was, by virtue of the sample selection criteria: (1) the individual primarily responsible for providing consistent assistance and attendant care to an individual with HIV illness, yet was not a trained professional, (2) providing care for a minimum of six months and not to exceed five years, (3) 18 years of age or older, and (4) due to the nature of the data, able to speak, read, and understand English. No control for gender or relationship was made. Written response to the questionnaire implied consent to participate in the study.

The participants were each provided with a cover letter explaining the study (see Appendix B), an informed participation statement (see Appendix C), a questionnaire (see Appendix D), and a stamped return envelope.

Data Gathering Process

Caregiver participation was initially requested in newsletters published by local Bay Area AIDS support groups and agencies (see Appendix A). Individuals were provided with the option of participating in an interview (in person or by telephone) or a written questionnaire. The questionnaire was estimated to take approximately 15 to 20 minutes to complete. Due to the poor response from the newsletters advertisements, additional efforts were necessary.

Fliers were designed and printed in eye catching colors and posted in hospitals, with concentration in HIV units, and in the Castro district in San Francisco (see Appendix E). Participants were requested to contact the researcher if interested in participating in the study. An additional incentive was added with the posting of signs - one completed questionnaire would be randomly selected to receive $50 cash or an equal contribution to a charity of the individual's choosing. The researcher also attended

assorted caregiver support meetings with a personal request for participation. The most successful drive for subjects was obtained through researcher personal request.

Of the 15 individuals who agreed to receive the questionnaire seven responses were received. Two of the seven responses were discarded secondary to the fact that they were not yet caregivers, but anticipating to be so in the future. Five responses were utilized in the pilot study.

Analysis of Data

Descriptive methods were used to analyze the data. Case data were organized using the Case Data Format (See Figure 1). Kielhofner's Continuum Model was used to describe factors of occupational function and dysfunction (See Figures 2, 3, and 4). An adaptation of Cubie and Kaplan's analysis for clinical cases was used (See Figure 5).

While the case studies present the data in an organized and summarized form, further analysis is needed to determine occupational function and dysfunction. A clear understanding of these terms is essential to enable therapists to assess the adaptation of the non-professional caregiver. The continuum model, put forth by Kielhofner (1985), presents the notion that :

> persons are occupationally functional when they: (a) act so as to satisfy society's expectations and need for productive and playful participation, and b) act so as to allow expression of exploration and mastery, and maintenance and enhancement of personal causation, values, interests, roles, habits, and skills

Figure 1

Case Data Format

Respondent #

Demographics:

Historical data:

Personal Causation:

Values:

Interests:

Roles:

Habits:

Skills:

Environment:

Figure 2

An Occupational Function/Dysfunction Continuum.

Levels of Occupational function	Levels of Occupational dysfunction
Achievement---Competence---Exploration	Inefficacy---Incompetence---Helplessness

Adapted from Kielhofner, (ed.) 1985.

Figure 3

Levels of Occupational Function

Achievement	**Competence**	**Exploration**
Striving to maintain and enhance performance in occupations with standards of performance and excellence.	Striving to be adequate to the demands of a situation by improving and/or shaping oneself to environmental tacks and expectations.	Curious investigation in a safe environment aimed at discovering potentials for action and properties of the environment.
Manifest in role performance of various types.	Results in the development of new skills and organization of skills into habits.	Results in innovation and in the development of skills.

(Adapted from Kielhofner, (ed.) 1985, p. 65)

Figure 4

Levels of Occupational Dysfunction

Inefficacy	**Incompetence**	**Helplessness**
A reduction of or interference with performance by dissatisfaction.	An inability to routinely and adequately perform.	Total or near total disruption of occupational performance.
A reduction of personal causation and negative impact on interests, values, roles, and habits may be present.	A major reduction in personal causation and impairment of interests, values, roles, habits and skills may be present.	Loss of personal causation, interests and values. Roles and habits may be absent or highly disorganized. Skills may be highly deficient.

(Adapted from Kielhofner, (ed.) 1985, p. 70)

Figure 5

Elements of Clinical Case Analysis

Primary questions	MoHO Components
1. Does the client anticipate successful outcomes of action?	Personal Causation
2. Does the client have valued goals?	Valued Goals
3. Does the client have interests?	Interests
4. Does the client have primary occupational roles?	Roles
5. Does the client have organized habit patterns?	Habit Patterns
6. Does the client have performance skills to carry out valued activities?	Skills
7. Does the environment support competent and consistent use of skills?	Environment

(Adapted from Kaplan and Cubie, 1982)

> and their constituents. Conversely, a person is occupationally dysfunctional when: (a) societal demands and expectations for productive and playful participation are not met and/or (b) behavior does not fulfill the urge to explore and master or threatens the disruption of the system's components. (p. 63)

Kielhofner's definition described a process rather than a static state, hence the utilization of a continuum. The continuum proposed by Kielhofner portrays three levels of occupational function and three levels of occupational dysfunction (Figure 2).

Occupational function represents optimal arousal, accomplishment and involvement with the environment. The three levels are achievement, competence and exploration (Figure 3). Achievement represents the highest level of occupational function. Characteristics of an achieving person include a future orientation, ability to envision goals, a belief in internal control and in personal skills which they continue to seek to monitor and improve, and expectancy of success based on self-development. The greatest reward for an achiever is the pleasure obtained through the involvement with the activity itself. Competence involves being recognized as adequate by one's peers to deal effectively with the environment and the ability to shape one's behavior based on feedback. At the competence level an individual builds his or her skills in anticipation of greater mastery. The third and least arousing level of occupational function is exploration. Essential to exploration is a safe and nurturing environment. Although at this level skills are not expected to be high, without a nurturing environment the development of skills is limited. Adults experience exploration when they experience a change in roles. Exploration as tied to function promotes a sense of excitement and curiosity with an optimistic outlook about the environment where meaningful opportunities are possible (Kielhofner, 1985).

In contrast to occupational function, occupational dysfunction represents stress and lack of involvement with the environment. The three levels of dysfunction are inefficacy, incompetence and helplessness (Figure 4). Inefficacy occurs when there is a disruption and dissatisfaction with the performance of meaningful activity. Characteristic of inefficacy is a decrease in personal causation, decrease in belief of efficacy or ability to obtain goals, and decreased meaningfulness in the daily activities of life. Roles are frequently disrupted at this level. An even further reduction in personal causation occurs at the level of incompetence. A sense of loss of control, feelings of anxiety and depression, and a separation from values and interests is common. Role performance is frequently disrupted with decreased skill resulting in negative feedback on one's performance. The ultimate extreme of stress and lack of involvement may occur at the level of helplessness where an individual is so traumatized that he or she is unable to find any value in the subcomponents, leaving them potentially dependent for their daily care. (Kielhofner, 1985)

The continuum model provided a framework that views occupational behavior from highly organized to highly disorganized. Its strengths include the incorporation of examining an open system cycle, the environment, along with a general exploration of the subsystems and their components. This method provides a range of levels of adaptive or maladaptive occupational functioning. It fails, however, to be a sensitive enough measure to define occupational function and dysfunction. Most individuals are generally able to identify with different levels of function at the same time. The case data present specific areas which allow for identification and differentiation of potential problem areas and yet to fit this data into the continuum model would require gross generalizations and assumptions without further investigation. The continuum model, while providing a glimpse at a degree of function and/or dysfunction, provides some valuable general

principles and a background to further define occupational function and occupational dysfunction as documented in the case data.

Kaplan and Cubie (1982) have presented a method for analyzing clinical cases which is based on ten primary questions derived from the Model of Human Occupation. The data gathering as well as the review and analysis of the data were tied to the relevant categories outlined in the primary questions. This method provides a clear relationship between theory base, data gathering, data analysis, and treatment planning. A variation of Kaplan and Cubie's analysis was utilized to assess and explore occupational function and dysfunction among the respondents in the pilot study.

Six primary questions related to the element of throughput were explored with an additional question addressing the environment. Questions pertaining to input, output, and feedback from Kaplan and Cubie's work were omitted in this study. Each question links a variable from the Model of Human Occupation to the data gathered. As an independent variable, a single element could be observed for function and/or dysfunction, but put together an entire system could be portrayed. The questions and their relationship to the model variables are shown in Figure 5.

Having utilized a Likert scaling system to gather most of the occupational performance data, scores of excellent (5) and good (4) were considered positive influences (+) and, hence, adaptive. Scores of poor (2) and very poor (1) were considered negative influences (-) with dysfunctional attributes. A rating of average (3) was considered as a possible negative influence (+/-) because the individual may be at risk of dysfunctional behavior. Figure 6 presents the form designed to categorize and summarize the case data for analysis.

This method of analysis exposed both functional as well as dysfunctional occupational adaptation at different levels within the same subsystem or component and

Figure 6

Data Analysis Recording Form

Primary Questions	**+/- Influence**
Respondent	#
Personal Causation:	
Sense of control over present life	
Change in sense of control	
Belief in caregiver skills	
Expectations for increasing skills	
***Lacks skills for caregiving	
Values	
Value of worker role	
Loss of valued role	
Value and meaningfulness of role in ADLS	
Interests	
Number of interests:	
Past	
Present	
Future	
Roles	
Loss of roles	
Balance between roles	
Enough time and energy to perform roles	
Habits	
Accommodate current roles	
Accommodate future roles/ goals	
Accomplish *needed* tasks	
Accomplish *wanted* tasks	
Ability to deal with change	
Belief in balanced life	

continued ...

Table 6 Continued

Skills	
Communication	
Decision making	
Problem-solving	
Time management	
Change in skills:	
Communication	
Problem solving	
Decision making	
Self confidence	
Anxiety	
Depression	
Time management	
Environment	
Physical	
Environmental	
Financial	
Social:	
Spending free time	
Utilizing assistance with caregiving	

separate areas of function and dysfunction. Using this method of analysis it is possible to distinguish separate areas of function and dysfunction.

Chapter 4

Data and Results

It has been proposed that adaptation is a way of viewing individual well-being in a broader context than the traditional concept of health which views health as merely the absence of disease or disability (Kielhofner, 1985). For the purpose of this study occupational function and dysfunction should be considered subcategories of the greater concept of human adaptation. This research advances the concept that human beings can be represented as an open system and comprised of three subsystems and their components. These principles provide the general background for exploring the research question:

Is the Caregiver Adaptation Research Evaluation Scale effective in determining occupational function and occupational dysfunction?

Case Data

Data gathered from five respondents are presented. Unique characteristics were apparent within each participant surveyed. Individualized responses were not limited to certain areas, but rather occurred randomly throughout each of the subcomponents. At least one variable was noted in each subsystem.

Respondent Caregiver # 1

Demographics: Male, 45 years old with a graduate degree

Historical data: Mate to care recipient, providing care for 1 year continuous, 2 1/2 years intermittently.

care recipient: 43 year old male, mental health - good, physical health - very poor

Personal Causation: Caregiver feels average sense of control over present life situation while experiencing and expressing a sense of decreased control; holds strong belief in caregiving skills and satisfaction/confidence with caregiver role; strongly expects success in increasing skills in the future.

Values: Places a high value on all roles. The value found in daily activities is also rated as very valuable.

Interests: Acknowledges a variety of interests from the past and for the future, but a definite decreased involvement in identified interests.

Roles: Maintains all past roles with exception of athlete, but reports a disruption among many of the roles. Believes a good balance between roles exists, but he does not have the time and energy required to perform all tasks of the various roles.

Habits: Habits reportedly accommodate current activities and the anticipation of future roles and goals; indicates ability to accomplish *needed* tasks on a regular basis with a decreased ability to accomplish *wanted* tasks.

Skills: Effectiveness in skills is varied with excellent communication skills, good problem-solving and decision making skills, and average time management skills. A decrease in time management skills was noted along with an increase in self-confidence, anxiety and depression.

Environment: No physical or environmental barriers to interfere with ability to perform caregiver role, but anticipates that financial constraints are an impending limitation. (Social) Interacts either alone or with friends in a variety of settings. Utilizes multi-disciplinary services to which he was introduced during a hospitalization of the recipient.

Respondent Caregiver # 2

Demographics: Male, 38 years old with an associate degree

Historical data: Friend to care recipient, providing care for 2 years,

care recipient: 44 year old male, mental health - poor, physical health - very poor

Personal Causation: Caregiver feels poor sense of control over present life situation, experiencing and expressing a sense of decreased control; holds a good belief in caregiving skills and satisfaction with the role; acknowledges lack of skills with only an average belief in ability to increase skills in the future.

Values: Identifies current work role as having no value. Of some value are volunteer and caregiver roles. Most valued past, present and future role is that of athlete. Holds future role of religious participant and hobbyist as being very valuable. Rates the value found in daily activities as being very valuable.

Interests: Acknowledges/identifies a large variety of interests from the past which continue.

Roles: Holds multiple roles with values ranging from no value to very valuable, worker and friend respectively. Expresses a poor balance among roles and insufficient time and energy to perform all tasks of the differing roles.

Habits: Habits reportedly accommodate current activities and the anticipation of future roles and goals; indicates ability to accomplish *needed* and *wanted* tasks on a regular basis. Reports lifestyle as being average for the most part, but does not believe that this lifestyle is balanced.

Skills: Well developed skills. Rates good effectiveness in communication with others, making decisions, problem-solving, and time management. Notes increase in these skills, but also an increase in anxiety and depression.

Environment: Limited physically by inability to lift weight, limited by environment barriers such as stairs and small bathroom, also limited financially ("I must work for a living."). (Social) Interacts with friends at home during free time. Utilizes outside resources including respite care.

Respondent Caregiver # 3

Demographics: Male, 46 years old with a graduate degree

Historical data: Mate to care recipient, providing care for 6 months,

care recipient: 36 year old male, mental health - good, physical health - poor

Personal Causation: Caregiver feels poor sense of control over present life situation, experiencing and expressing a sense of decreased control; lacks belief in caregiving skills; realistically expects success in increasing skills in the future.

Values: Identifies current work roles as having no value to little value; reports decreased value in current and old roles; Value found in daily activities is moderate.

Interests: Acknowledges a variety of interests from the past and for the future, but a definite decreased involvement in identified interests.

Roles: Lost student, athlete, and hobbyist roles during transition to caregiver role. Retains many of old roles, but with less value and enjoyment. Believes a good balance between roles exists, but he does not have the time and energy required to perform all tasks of the various roles.

Habits: Habits reportedly accommodate anticipation of future roles and goals; indicates ability to accomplish *needed* tasks on a regular basis with a decreased ability to accomplish *wanted* tasks.

Skills: Highly developed skills. Rates excellent effectiveness in communication with others, making decisions, problem-solving, and time

management. Notes increase in these skills, but also an increase in anxiety. Also noted decreased frequency of depression.

Environment: No physical, environmental barriers or financial limitations to interfere with ability to perform caregiver role. (Social) Interacts with friends at home during free time, decreased amount of time spent out in community than in past. Apparently does not seek out resources and opportunities in the environment.

Respondent Caregiver # 4

Demographics: Male, 37 years old with a bachelor degree

Historical data: Mate to care recipient, providing care for 12 months,

care recipient: 36 year old male, mental health - good, physical health - poor

Personal Causation: Caregiver feels poor sense of control over present life situation, experiencing and expressing a sense of decreased control; excellent belief in caregiving skills and satisfaction in ability to perform role; acknowledges a lack of skills, but realistically expects success in increasing skills in the future.

Values: Identifies roles of caregiver and friend as very valuable , all other roles hold moderate value. Daily activities are highly valued. Expresses a loss of valued roles.

Interests: Acknowledges a variety of interests from the past and for the future, but a definite decreased involvement in identified interests.

Roles: Lost athlete and full-time worker role assuming a part-time worker role. Retains many of old roles, with an average value. Believes a poor balance between roles exists, and does not have the time and energy required to perform all tasks of the various roles.

Habits: Habits reportedly accommodate current activities and the anticipation of future roles and goals; indicates ability to accomplish *needed* and *wanted* tasks on a regular basis.

Skills: Rates skills of communication and problem solving as good with an average effectiveness in making decisions and poor effectiveness in time management. Notes decreased ability to communicate with others, to make decisions, and a decrease in self confidence and time management. An increase in anxiety was reported.

Environment: Reports being limited financially secondary to "not enough money to stay at home 24 hours". No physical or environmental barriers interfere with ability to perform caregiver role. (Social) Spends free time alone at home with no assistance. Apparently does not seek out resources and opportunities in the environment.

Respondent Caregiver # 5

Demographics: Male, 36 years old with a bachelors degree

Historical data: Friend to care recipient, providing care for 4 months,
care recipient: male, mental health - good, physical health - poor

Personal Causation: Caregiver feels average sense of control over present life situation, expressing no change in sense of control; holds an average belief in caregiving skills; realistically expects success in increasing skills in the future.

Values: Identifies current work role as very valuable followed by volunteer work, caregiving, and being a friend. An average value was identified for daily activities.

Interests: Continues to participate in a variety of interests from the past with anticipation of continuing them in the future; strong interest in returning to volunteer work.

Roles: Lost volunteer role, identified as being highly valued, during transition to caregiver role. Maintains full-time work role which is the role held as most valuable. Believes an average balance between roles exists, but he does not have the time and energy required to perform all tasks of the various roles.

Habits: Habits reportedly accommodate current roles and the anticipation of future roles and goals (average); indicates ability to accomplish *needed* tasks on a daily basis with an average ability to accomplish *wanted* tasks. Reports poor ability to deal with changes in daily plans.

Skills: Well developed skills. Rates good effectiveness in communication with others, making decisions, and problem-solving, and average effectiveness in time management. Reports no change in skills since becoming a caregiver.

Environment: Biggest limitation interfering with ability to perform caregiver role is financial. He is unable to provide full-time care because of the need to work full-time. There exists no physical or environmental barriers. (Social) Interacts primarily with lover at home. Obtains information from physician and occasionally utilizes respite care.

A review of the case data revealed that variations were noted in personal causation. Caregiver respondent # 1 was the only individual to express a strong sense of his ability to increase his caregiving skills in the next few months. All others were at risk for occupational dysfunction, expressing uncertainty regarding their ability to increase skills. Caregiver respondent # 5 also presented a variation in that he was the only individual to express experiencing an increase or positive change in his sense of control.

As for values and interests, caregiver respondents # 2 and # 3 revealed that their current roles of worker held little to no value. Caregiver respondent # 2 was the only person who did not indicate that he had experienced a significant decrease in current interests. While all respondents reported a disruption in roles, caregiver respondents # 2 and # 4 indicated that the disruption has caused a poor balance among roles to occur. Respondent # 4 also reported having to switch from a full-time to a part-time position.

Respondent # 5 was the individual noted to be at greatest risk of occupational dysfunction regarding habits. An average grade was given regarding his habits supporting current and future roles and goals as well as his ability to accomplish wanted tasks. Respondent # 1, however, was the single respondent to clearly express occupational dysfunction regarding his ability to accomplish wanted tasks. Respondent # 3 was the individual noted to be most functional in the subsystem of habits. # 3 reported that habits supported both current and future roles and goals. This was also the only individual to report a belief that he had a balanced life.

Strong skills were reported throughout with exception of respondent # 4 who reported poor time management skills. Respondent # 4 also was the only person to report a decrease in ability to communicate and to make decisions and in self confidence. Increased anxiety and depression were common among all individuals except # 3 who actually reported a decrease in depression.

Respondent # 2 was the only individual to indicate dysfunctional attributes in the physical, environmental and financial areas. This individual reported that he had a bad back which limited his ability to be of physical assistance and that the recipient of his care was wheelchair bound and the environment in their home was not fully wheelchair accessible. All participants except # 3 were concerned about their financial situation. On

the social front, # 4 was the only individual to indicate that he spent all of his free time alone and without any assistance.

Figure 7 presents the findings of occupational function, dysfunction and potential areas for dysfunction among the five respondents surveyed.

Research Question

Is the Caregiver Adaptation Research Evaluation Scale effective in determining occupational function and occupational dysfunction?

This pilot study indicated that occupational functional and dysfunction can be determined with the Caregiver Adaptation Research Evaluation Scale . Occupational function and dysfunction were apparent in all of the components. A greater number of respondents (3 to 4 out of 5) indicated functional adaptation in personal causation as related to their belief in the efficacy of their caregiver skills, others' perceptions of them, and their degree of satisfaction and/or confidence in their ability to perform the caregiver role. Dysfunctional adaptation, however, was also evident in that a majority of the respondents reported a poor sense of control over their present life situation and a unanimous report of a sense of decreased control.

The most notable area where adaptive occupational functioning was noted was in the skills component. Respondent reports of overall effectiveness in communicating with others, making decisions and problem-solving were all rated highly. Reports of increased skills in the same areas were also highlighted by a number of respondents.

While no respondent demonstrated a lack of roles, there was evidence of loss of roles by all and, by report, a disruption in the balance between roles. Habit patterns tended to support current roles, but there was an increased uncertainty about the ability of

Figure 7

Occupational Function, Dysfunction and Potential Dysfunction

Respondent	#1	#2	#3	#4	#5
Personal Causation:					
Sense of control over present life	+/-	-	-	-	+/-
Change in sense of control	-	-	-	-	+
Belief in caregiver skills	+	+	+/-	+	+/-
Expectations for increasing skills	+	+/-	+/-	+/-	+/-
***Lacks skills for caregiving	Yes	Yes	Yes	Yes	Yes
Values					
Value of worker role	+	-	-	+/-	+
Loss of valued role	-	-	-	-	-
Value and meaningfulness of role in ADLS	+	+	+/-	+	+/-
Interests					
Number of interests:					
Past	+	+	+	+	+
Present	-	+	-	-	+/-
Future	+	+	+	+	+
Roles					
Loss of roles	+/-	-	-	-	-
Balance between roles	+	-	+	-	+/-
Enough time and energy to perform roles	-	-	-	-	-
Habits					
Accommodate current roles	+	+	+	+	+/-
Accommodate future roles/ goals	+	+	+	+	+/-
Accomplish *needed* tasks	+	+	+	+	+
Accomplish *wanted* tasks	-	+	+	+	+/-
Ability to deal with change	+/-	+/-	+	-	-
Belief in balanced life	No	No	Yes	No	No
Skills					
Communication	+	+	+	+	+
Decision making	+	+	+	+/-	+
Problem-solving	+	+	+	+	+
Time management	+/-	+	+	-	+/-

Continued ...

Figure 7 Continued

Change in skills:					
Communication	•	+	+	-	•
Problem solving	•	+	+	•	•
Decision making	•	+	+	-	•
Self confidence	⇑+	⇑+	+	-	•
Anxiety	⇑-	⇑-	⇑-	⇑-	•
Depression	⇑-	⇑-	⇓	•	•
Time management	-		+	-	•
Environment					
Physical	+	-	+	+	+
Environmental	+	-	+	+	+
Financial	-	-	+	-	-
Social:					
Spending free time	+	+/-	+	-	+/-
Utilizing assistance with caregiving	+	+	-	-	+

Note. + = occupational function
– = occupational dysfunction
+/– = At risk of occupational dysfunction
• = no change

current routines to support future roles and goals. While numerous indicators supported functional adaptation with roles, all five surveyed indicated that they did not have the time or energy required to perform all the tasks of the different roles. Most respondents felt that they were able to accomplish daily tasks that were *needed* between 3-4 and 5-6 times a week and accomplish those things that they *wanted to* accomplish between 3-4 and 1-2 times a week.

Respondents demonstrated a strong sense of value regarding meaningfulness of being a caregiver and the daily activities involved with that role. The role of caregiver was selected most frequently as holding the most value. All respondents indicated a loss of valued roles.

All respondents reported (1) a decreased involvement in current interests and (2) a desire to return to old/recent interests in the future. This demonstration of forward orientation demonstrates a direction of functional adaptation.

Environmental factors such as physical limitations and environmental barriers did not interfere with 4 of the 5 respondents' ability to perform as a caregiver. The inability to lift much weight, the presence of stairs and inability to maneuver well in the bathroom were the factors attributed to interfering with the one individual's ability to perform the caregiver role fully and adequately. All the participants indicated that they spent their social time at home; three of the five surveyed indicated that they spent most of their free time with friends; two indicated that they spent their free time alone or with their mate (care recipient).

The following areas of dysfunction were identified in the pilot study.

Beliefs and perceptions of the respondents indicated that they were comfortable with their new roles. A further look into the elements of personal causation including sense of internal and external control and a sense of a change in control, however, showed

a greater variance with all respondents reporting a decrease in their sense of control. Although respondents indicated belief in their skills and ability to perform the caregiver role, when questioned further, all individuals reported that there were indeed skills they were lacking (Figure 8). Three out of five respondents also expressed reservations regarding their ability to successfully increase their skills over the next few months.

Although all survey participants indicated a desire to return to lost interests, an examination of the lost activities reveals an area of concern and dysfunction. Activities frequently eliminated are listed in Table 1. Some individuals reported a decline in interests of up to 70 % . Decreased involvement in caring for oneself (exercise, self-enrichment and leisure) inhibits the balance associated with functional adaptation.

The most valued goals appeared to be related to the caregiver role. Other identified current roles were given a lower value by all when compared with the caregiver role. However, while value was evident, the balance that existed between roles was leaning towards dysfunctional levels. Habits failed to support role resolution. Respondents did not see current daily routines supporting their future roles and goals, nor did they feel good about the efficiency of the use of their time or their ability to deal with change. When asked to describe their lifestyle for balance there were split reports ranging from good (1), average (2) to poor (2). When asked if they believed they lived a balanced life four out of the five reported "no".

The skills noted as dysfunctional were increased frequency of anxiety and increased frequency of depression.

The greatest environmental factor inhibiting occupational functioning was financial limitation. Socially, all but one individual reported support primarily from friends. The same individual reported having no one to assist with the caregiver role nor utilization of outside healthcare providers for assistance.

The research Caregiver Adaptation Research Evaluation Scale apparently was successful in its goal of determining general as well as specific areas of occupational function and dysfunction. The instrument is less effective, however, in delving into the values these caregivers hold regarding specific aspects of their lives. The instrument was limited to assessing values placed on roles and interests, along with the general concept of activities of daily living. Missing from the data is an assessment of an individual's values directed at temporal orientation, personal standards, and a closer examination of occupational goals and the meaningfulness of activity. Roles are briefly explored in the assessment, touching upon perceived incumbency and ones personal belief about role balance.

Figure 8

Skills Respondents Identified as Lacking

Humor
Enthusiasm
Ability to take control of situation
General medical knowledge
Basic knowledge of the disease
Knowledge about care procedures
Patience
Awareness of support services
Bureaucratic skill for dealing with medical establishment and insurance
Companies

Table 1

Most Frequently Eliminated Activities Since Assuming Caregiver Role (N=5)

Activity	Frequency selected
Volunteer work	4
Travel	4
Entertaining	4
Visiting friends	3
Shopping	3
Exercising	3
Taking classes/attending lectures	3

Chapter 5

Summary, Implications and Recommendations

Summary

The purpose of this study was to develop a research instrument using the Model of Human Occupation to assess areas of occupational function and dysfunction among non-professional caregivers. The research was also intended to determine the usefulness of the Caregiver Adaptation Research Evaluation Scale through the process of a pilot study. The question was posed: Is the CARES effective in determining occupational function and/or dysfunction. An extensive literature review indicated that while many health professionals have addressed specific areas of potential concern for individuals assuming the caregiver role, these areas are limited to isolated and general areas such as psychological, physical, and social needs, or social supports and roles and interrelational problems. Literature supports the idea that what is missing is an assessment that combines a comprehensive, holistic view of the caregiver while adhering to an established model. This research provided an instrument based on the Model of Human Occupation that assesses an individual holistically, categorically, and with specific attention to areas of occupational function and dysfunction. The pilot study supported the usefulness of the Caregiver Adaptation Research Evaluation Scale and provided a means for determining occupational function and dysfunction. Since areas of occupational function and dysfunction among the non-professional caregivers were found, these findings can serve as a foundation for further research and intervention.

For this research, a pilot study was conducted. Fifteen caregivers to individuals with the HIV illness agreed to participate in the study. Of the seven responses returned, five surveys were usable. The poor return is a strong indicator that although these individuals may have had a desire to participate in the study, they may have been unable to find the time necessary to do so. It gives pause to thinking -- what else is being missed in these caregiver's lives?

Areas of occupational function and dysfunction were found in all of the subsystems and their components.

Implications

Information revealed by this research has several implications for the practice of occupational therapy. Of particular value are the areas determined to be occupationally dysfunctional for these are the areas where intervention could and should be implemented. Occupational dysfunction was apparent in all of the components of the volitional subsystem. Reports of (1) a poor sense of control over one's present life, (2) a change in one's sense of control, and (3) a belief that skills were lacking among one's caregiver skills were areas identified within personal causation. Possible intervention strategies could include, but would not be limited to the following:

1) Identification of areas where the individual is making choices and assisting him to gain control; providing opportunities for decision making.

2) Provision of realistic guidelines for independent decision making.

3) Identification of resources where individuals would be able to obtain skills, checking the validity or appropriateness of their feelings by consulting with others, primarily the recipients of their care, to determine their views and exploring previous examples and past situations where the individuals' actions contradicted their feelings of inefficacy and sense of external control.

Through values clarification, individuals can explore discrepancies between values and actual performance. A loss of a valued role can be addressed by refocusing goals with current abilities and by reinforcing the need for flexibility. Attempting to identify aspects of that role in daily activities is also recommended. An identified decreased involvement in valued interests also provides the opportunity to explore and modify involvement in continued interests. Problem solving regarding how to accomplish valued interests given their current situation may be explored as well. Maintenence of a forward orientation regarding returning to these activities was evident in individuals surveyed and should be recognized and supported.

The habituation subsystem revealed dysfunctional attributes primarily within the component of roles, but also among habits. All respondents reported a loss of roles. Treatment may address identifying the skills and abilities of the values attached to those roles followed by determining possible partial incorporation of them into current roles, and/or suggestions for participation in new or previously less important roles. Not having

enough time and or energy to perform the activities of all the roles was also identified. An essential concept for these individuals to be exposed to is that they must learn that role obligations are not rigid, but flexible. Identification of external resources to provide assistance may be performed as well as addressing the individual's skills in time management. While most respondents reported that their habits supported current and future roles and goals, all but one respondent indicated that their lives were not balanced and they had difficulty dealing with change. Intervention for these areas would first address recognition of the need to increase habits followed by monitoring the development of habits that emphasize time management, energy conservation, and the balance of time use. Individuals should be assisted in exploring and prioritizing activities to set realistic goals and then assisted in creating a balanced routine. Again, the need to recognize the importance of flexibility should be addressed.

The performance subsystem, while at the lowest point of the hierarchy, is envisioned as being the subsystem that facilitates the production of behavior. Without the development of skills, purposeful behavior is hindered. Respondents rated their skills highly with the exception of time management. It was also noted that most respondents had experienced an increase in anxiety and depression. As indicated by the preceding areas of occupational dysfunction and the recommended intervention, it is possible to see that, although one's belief in skills may be high, there are indeed areas that require skill

development. These skills include time management, decision making, problem solving, personal interaction, and personal processing to name a few.

Environmental factors inhibiting full occupational functioning were primarily financial, although physical limitations as well as environmental limitations were also identified. On the social aspect, it was detected that these caregivers were frequently spending their free time alone and at home. Although only two respondents reported receiving no assistance with their caregiver duties, this is an area where, if any occupational dysfunction is detected, it should and could be readily treated. With resources for finances and respite care available, many of these individuals could again become occupationally functional.

The CARES appears to be a valuable tool to assist in determining areas of occupational function and or dysfunction among the population of non-professional caregivers. Although it is intended to be useful to multi-disciplines, it is of primary importance to occupational therapy, for it is through development and use of appropriate instruments that professions can define and develop themselves. An instrument such as CARES, based on an accepted frame of reference, can help to refine occupational therapy theory, further strengthening the profession. The continued investigation of its feasibility as an evaluation tool is indicated. This study can serve as a model in this research.

Recommendations

This study points to several areas where further research is warranted. As the pilot study was limited to a sample of five, additional studies are indicated to examine the effectiveness of the CARES in determining occupational function and dysfunction as well as to determine the validity of the instrument. Further research exploring occupational function and dysfunction can help build a data base and, hence, treatment interventions to address additional areas of occupational dysfunction. Such studies could also be used to explore and identify patterns of occupational function and dysfunction among various non-professional caregivers. All of the recommended studies would assist in refining the theory on which it was based.

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APPENDIX A

REQUEST FOR PARTICIPATION

Caregivers Input Needed

Maureen Vaughan Ruscher, a registered occupational therapist, is performing a survey of caregivers to individuals with HIV. The purpose of the study is to determine how individuals are adapting to the added role of being a non-professional caregiver and the factors which contribute to functional adaptation and/or dysfunctional adaptation. Gaining current information on these issues will help to assess, and develop effective interventions, to support the caregiver so that optimum care for PWA can be given.

Participants should be:

- Individuals primarily responsible for providing consistent assistance and care to an individual with HIV.
- Not a trained professional caregiver.
- Have been providing care for a minimum of 6 months and not to exceed 5 years.
- 18 years or older
- Speaks English as a primary language.

The caregivers will be asked to participate in either an interview and/or a written questionnaire. For more information, call (707) 539-5423 or call Maureen Vaughan Ruscher collect at (408) 257-2558.

Caregivers Input Needed for San Jose State Study.

Maureen Vaughan Ruscher, a registered occupational therapist, is performing a survey of caregivers to individuals with HIV. The purpose of the study is to determine whether individuals are adapting functionally or dysfunctionally to the added role of being a non-professional caregiver and the factors which contribute to functional adaptation and/or dysfunctional adaptation. Gaining current information on these issues will help to assess, and develop effective interventions, to support the caregiver so that optimum care for PWA can be given.

Participants should be:

Individuals primarily responsible for providing consistent assistance and care to an individual with HIV.

Not a professional trained caregiver.

Have been providing care for a minimum of 6 months and not to exceed 5 years.

18 years old or older

Speaks English.

The caregiver will be asked to participate in either 45-60 minute interview or a written questionnaire. For more information , contact Maureen Vaughan Ruscher 408-257-2558

APPENDIX B

COVER LETTER

Dear Caregiver,

Much research has been done and continues to be done on the needs of individuals infected with HIV, but little has been published on the impact this diagnosis has had on the people who are caring for these individuals. Studies have shown that People With AIDS (PAW) are surviving for significant periods of time after diagnosis and are well enough to live outside a hospital setting provided with various amount of assistance. Family and friends are increasingly finding themselves in the unanticipated and unprepared for role of caregiver.

I am a registered occupational therapist conducting a study on (1) how individuals' are adapting to the added role of becoming a caregiver, and (2) the factors that facilitate adaptation and the factors that inhibit adaptation. I am also interested in hearing from you what your needs are. It is only through research that we can gather information on these issues which will help to assess and to develop effective interventions to support caregivers like yourself so that optimum care for PWA is provided and caregiver burnout and dysfunction is avoided and/or remedied.

I am aware of the many time, physical, and emotional demands you currently have so I have intentionally kept the survey short to facilitate your participation I this study. Please help yourself and others by agreeing to participate in this study.

No names will be used and all information will be kept safe in my possession. If you have any additional questions please feel free to phone me.

Thank you for your time thus far. I hope that through your assistance in this study I will be able to facilitate providing support to you and others like you in the future. Thank you.

Respectfully,

Maureen Vaughan Ruscher
(408) 257-2558

APPENDIX C

STATEMENT OF PARTICIPATION IN RESEARCH

SAN JOSE STATE UNIVERSITY

A campus of The California State University

College of Applied Sciences and Arts • Department of Occupational Therapy
One Washington Square • San José, California 95192-0059
Main Office: 408/924-3070 • Fieldwork Office: 408/924-3078 • FAX: 408/924-3088

INFORMED PARTICIPATION STATEMENT
SAN JOSE STATE UNIVERSITY

RESPONSIBLE INVESTIGATOR: Maureen Vaughan Ruscher

TITLE OF PROTOCOL: A Study of Non-professional Caregivers to Individuals with Human Immune Virus (HIV) Illness: The Ability to Adapt to the Added Role, and the Factors which Contribute to Funcitonal and Dysfunctional Adaptation.

I have been asked to participate in a research study that is investigating how individuals are adapting to assuming the caregiver role to an individual with the HIV illness, and what the inhibiting and facilitating factors for successful adaptation.

I understand that

1) I will be given the option to either A) answer a questionnaire in the privacy of my home or B) answer similar questions in a face-to-face interview at either my home or the local support center I am involved with. The decison as to location is mine. The duration of the interview is not to exceed 45-60 minutes.

2) no anticipated risks are expected.

3) the possible benefits of this study to me are that my needs may be recognized for the purpose of creating assistive services.

4) the results from this study may be published, but any information from this study that can be identified with me will remain confidential and will be disclosed only with my permission.

5) any questions about my participation in this study will be answered by Maureen Vaughan Ruscher at 408-257-2558. Complaints about the procedures may be presented to Lela Llorens, Ph.D. at 408-924-3070; Chair, Department of Occupational Therapy. For questions or complaints about research subject's rights, or in the event of research-related injury, contact Serena Stanford, Ph.D. (Associate Academic Vice President for Graduate Studies and Research) at 408-924-2480.

6) my consent is given voluntarily without being coerced; I may refuse to participate in this study or in any part of this study, and I may withdraw at any time, without prejudice to my relation with SJSU or my local support center.

You may keep this copy for your information. Completing and returning the questionnaire indicates your decision to participate in the study.

APPENDIX D

CAREGIVER ADAPTATION RESEARCH EVALUATION SCALE

QUESTIONNAIRE

Statement of Consent

I have been informed of my rights as a research participant. By completing this questionnaire I am giving my consent for the information obtained to be used for educational, research and publication purposes. Please check the box to indicate that you have read and understand this statement. [ ]

Please answer each question as accurately as you can by placing a mark on the line preceding the answer that you select, or by entering information as requested in the space provided.

All of your answers are strictly confidential. If for any reason you do not wish to answer a question, please circle the question so that I know you intentionally skipped it.

Part I - DEMOGRAPHICS

1. Gender ____ M ____ F

2. Age: _____

3. Relationship to Care recipient:
   ____ parent ____ family member
   ____ mate ____ friend
   ____ other (specify)_____

4. Highest level of education:
   ____ high school ____ bachelors degree
   ____ vocational school ____ graduate degree
   ____ associates degree ____ post graduate degree

5. Is English your primary langauge? _____ Yes _____ No

6. Are you, by profession, trained to be a caregiver? _____ Yes _____ No

7. How long have you been providing care? _____

8. Are you the individual primarily responsible for providing daily care to an individuals with HIV? _____ Yes _____ No

9. Age of the recipient of your care: _____

10. Gender of the recipient of your care: ____ M ____ F

11. Please rate the general mental health of the recipient of your care.

    _____ excellent _____good _____average _____poor _____very poor

12. Please rate the general physical health of the recipient of your care.

    _____ excellent _____good _____average _____poor _____very poor

Part II

1. Please rate, overall, your level of satisfaction with your ability to adapt to becoming a caregiver?

   _____ excellent _____good _____average _____poor _____very poor

2. How much control do you feel you have over your present life situation?

   _____ excellent _____good _____average _____poor _____very poor

3. How has your sense of control changed since becoming a caregiver?

   _____ increased _____decreased _____no change

4. Rate how relevant YOU BELIEVE your skills are for being a caregiver?

   _____ excellent _____good _____average _____poor _____very poor

5. Rate your level of satisfaction/confidence in your ability to fulfill the role of caregiver?

   _____ excellent _____good _____average _____poor _____very poor

6. How do others perceive your ability to perform the caregiver role?

   ____ excellent ____good ____average _____poor _____very poor ____don't know

7. Are there skills you feel you are lacking and need to develop? ___No ___Yes
   Please list:_____
   _____

8. Please list the steps you have taken to increase your skills and/or confidence.
   _____ Not applicable
   _____ read literature
   _____ attended lectures
   _____ attended courses
   _____ support groups
   _____ other (specify): _____
   _____

9. Over the next few months, how successful do you think you will be in increasing your skills and/or confidence?

   _____ excellent _____good _____average _____poor _____very poor

10. What was your motivation for becoming a caregiver? (Check ALL that apply)
    _____ lack of other options
    _____ family obligation
    _____ affection
    _____ reciprocity
    _____ freely chose
    _____ others expectations of me
    _____ other (Specify)_____

11. Please rate the level of meaningfulness you derive from being a caregiver.

_____ excellent _____good _____average _____poor _____very poor

12. Please rate the value you find in your daily activities by circling a number.

5	4	3	2	1
very valuable		somewhat valuable		no value

13. What do you find meaningful in your daily life?

_____

_____

14. When asked "what do you do", what do you say? I am a(n) _____ (fill in)

15. On the list provided please:
A) check all roles you can identify with occupying in the PAST/PRESENT/FUTURE.
B) circle which roles have been disrupted since becoming a caregiver.

	PAST	(A) PRESENT	FUTURE	(C) VALUE
Student				
Worker: -Fulltime				
-Parttime				
Volunteer				
Caregiver				
Home maintainer				
Friend				
Parent				
Family member: (Specify:_____)				
Religious participant				
Hobbyist/amateur				
Participant in organization				
Athlete				
Other (Specify:_____)				
Ex. Athlete	X		X	4

C) Using the scale provided, please indicate how valuable each role is to you.

5	4	3	2	1
very valuable		somewhat valuable		no value

16. How would you rate the balance that exists between your roles?

_____excellent _____good _____average _____poor _____very poor

17. Do you have the time and energy required to perform all tasks of your differing roles? _____Yes
_____No

18. How many hours each day are devoted to caregiving?_____

19. Is this more than you anticipated? _____Yes
_____No

20. How do you anticipate this changing over the next 6 months?

_____ increasing _____decreasing _____no change _____don't know

21. How well do you believe your current daily routine and activities supports your roles?

_____excellent _____good _____average _____poor _____very poor

22. How well do your current daily routines and activites support your anticipated future roles and goals?

_____excellent _____good _____average _____poor _____very poor

23. Please rate the efficiency of your use of time.

_____excellent _____good _____average _____poor _____very poor

24. How balanced would you describe your lifestyle?

_____excellent _____good _____average _____poor _____very poor

25. How often are you able to accomplish the things you <u>need</u> to each day?

_____everyday _____5-6x/wk ____3-4x/wk _____1-2x/wk _____never

26. How often are you able to accomplish the things you <u>want</u> to each day?

_____everyday _____5-6x/wk ____3-4x/wk _____1-2x/wk _____never

27. Rate how well you deal with changes in your daily plans?

_____excellent _____good _____average _____poor _____very poor

28. Are weekends different from weekdays? _____Yes _____No

If YES, how? _____

_____

29. Do you believe you live a balanced life? _____Yes _____No

If NO, what is missing?_____

_____

30. Using the following table please check all activities you :

A) Enjoyed in your PAST
B) Enjoy CURRENTLY
C) Would like to enjoy in the FUTURE

	A	B	C		A	B	C
playing a musical instrument				social clubs			
singing				drama groups			
ceramics				discussion groups			
art (drawing,painting)				church organizations			
needlework/sewing				community action group			
leatherwork				political organizations			
small handicrafts				PTA			
woodworking				volunteer work			
building models				bicycling			
restoring furniture				kite flying			
fixing things				swimming			
car repair				jogging			
electronics				driving			
gardening				hiking			
puzzles				skating (roller/ice)			
reading				collecting			
lectures				lifting weights			
attending a class				skiing (snow)			
hunting				water skiing			
writing				baseball &/or basketball			
traveling				camping			
history				bowling			
poetry				ping pong			
watching TV				golf			
listening to music				tennis			
taking care of a pet				karate/judo			
movies/concerts				caring for plants			
shopping				cooking/baking			
visiting friends				playing cards			
dating				entertaining			
going out to restaurants				home repairs			
other:( )				other:( )			

(Adapted from Matsutsuyu, Janice, The Interest Check list.)

31. On the above table, please circle any/all activity you have partaken in the past seven days

32. Please rate your overall effectiveness in the following areas by marking an "X" on the scale provided.

		5 excellent	4 good	3 average	2 poor	1 very poor
A)	communicating with others					
B)	making decisions					
C)	problem-solving					
D)	time management					

33. Since becoming a caregiver, please describe the changes you have noticed in the following areas:

	Decreased	Increased	No Change
a) ability to communicate with others	_____	_____	_____
b) ability to make decisions	_____	_____	_____
c) ability to problem solve	_____	_____	_____
d) level of self confidence	_____	_____	_____
e) level/degree of anxiety	_____	_____	_____
f) frequency of depression	_____	_____	_____
g) time management	_____	_____	_____

34. Do you have any physical limitations which interfere with your performing as a caregiver?

_____No _____Yes

(Specify) _____

35. Do you have any environmental barriers in your home or community that interfere with your performing as a caregiver?

_____No _____Yes

(Specify) _____

36. Do you have any financial limitations which interfere with your performing as a caregiver?

_____No _____Yes

(Specify) _____

37. How do you spend most of your free time? (Check ONE)

_____alone _____family
_____friends _____community
_____other (specify)_____

38. In what setting?

_____home _____school
_____workplace _____neighborhood
_____support center _____other (specify)_____

39. Is there anyone who assists you with the role of caregiver?

_____No _____Yes (Specify) _____

40. Which of the following healthcare providers do you obtain regular assistance from?

_____social services _____nursing
_____physical therapy _____occupational therapy
_____individual &/or family therapy _____physician
_____other (Specify)_____

41. Who provides support and comfort to you? (Check all that apply)

_____ No one
_____ family member
_____ friend
_____ religious leader
_____ professional
_____ other (specify)_____)

42. How do others provide support? (Check all that apply)

_____ not applicable
_____ listen
_____ reassure
_____ talk about what is bothering the person seeking support
_____ hold or hug person seeking support/comfort
_____ offer encouragement/praise
_____ respite
_____ other (specify)_____

43. What do you do to care for yourself and/or to relieve stress? (Check all that apply)

_____ nothing
_____ take walks
_____ read a good book
_____ exercise
_____ listen to music
_____ use relaxation techniques
_____ talk to someone
_____ say "NO" occassionally
_____ other (specify) _____

44. Please list the factors you feel have helped you adapt to your caregiver role.

_____

_____

45. Please list the factors which have inhibited your adaptation process.

_____

_____

46. What would further assist you in adapting to your role of caregiver?

_____

_____

47. Please rate, overall, how satisfied you are with your adaptation to becoming a caregiver?

_____ excellent _____good _____average _____poor _____very poor

THANK YOU FOR YOUR TIME, THOUGHTS, AND CONTRIBUTION.

APPENDIX E

FLIERS

LOVING CAN BE PAINFUL ---

----BUT IT'S NOT SUPPOSED TO BE DISABLING

Caregivers. . .
how are you adapting?

Caregiver Input needed for San Jose State Study.

Maureen Vaughan Ruscher, a registered occupational therapist, is performing a survey of caregivers to individuals with HIV. The purpose of the study is to determine how individuals are adapting to the added role of being a non-professional caregiver and the factors which contribute to functional and dysfunctional adaptation. Gaining current information on these issues will help to assess and develop effective interventions to support the caregiver so that optimal care for Persons With AIDS can be given.

Participants should be:

- Individuals primarily responsible for providing consistent assistance and care to an individual with HIV.
- Not a professionally trained caregiver.
- Have been providing care for a minimum of 6 months and not to exceed 5 years.
- 18 years old or older
- Read, speak and understand English

Participant involvement:

- A written questionnaire, to be answered at your convenience and returned in a self-addressed, stamped envelope to the researcher. (Phone interviews are possible if desired.)
- All information will be kept confidential.
- One completed questionnaire will be randomly selected to receive $50 cash or an equal contribution to a charity of the individual's choice.

No one can prepare for AIDS, but preparing for the caregiver role is possible.

Please, contribute another 15-20 minutes to help others like you adapt as successfully as possible. For more information, contact Maureen Vaughan Ruscher at (408) 257-2558. (Collect calls will be accepted.)

HELP!!!

Caregiver Input needed for San Jose State Study.

Have you come across anyone who meets the following criteria:

Participants should be:

- Individuals primarily responsible for providing consistent assistance and care to an individual with HIV.
- Not a professionally trained caregiver.
- Have been providing care for a minimum of 6 months and not to exceed 5 years.
- 18 years old or older
- Read, speak and understand English

Participant involvement:

- A written questionnaire, to be answered at your convenience and returned in a self-addressed, stamped envelope to the researcher. (Phone interviews are possible if desired.)
- All information will be kept confidential.
- One completed questionnaire will be randomly selected to receive $50 cash or an equal contribution to a charity of the individual's choice.

If you know of anyone who may qualify, PLEASE, respond in one of the following capacities:

1) enlist the individuals' participation directly through normal communications and/or by presenting the letter of introduction provided by the researcher.
2) call or send name and phone number to researcher at the contact numbers below.

About the researcher:

Maureen Vaughan Ruscher, a registered occupational therapist, is performing a survey of caregivers to individuals with HIV. The purpose of the study is to determine how individuals are adapting to the added role of being a non-professional caregiver and the factors which contribute to functional and dysfunctional adaptation. Gaining current information on these issues will help to assess and develop effective interventions to support the caregiver so that optimal care for Persons With AIDS can be given.

For more information, contact Maureen at: **(408) 257-2558**
22677 Royal Oak Way
Cupertino, CA 95014